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Človeški dejavniki (HF) - Personalizacija sistemov e-zdravje z uporabo uporabniških profilov e-zdravje

Human Factors (HF) - Personalization of eHealth systems by using eHealth user profiles (eHealth)

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by using eHealth user profiles (eHealth)

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Foreword

This ETSI Standard (ES) has been produced by ETSI Technical Committee Human Factors (HF).

Intended readers of the present document are:

- eHealth service providers;

- device manufacturers;

- software developers;

- researchers.

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Introduction

Adapting an eHealth system to the individual user is essential for making it safe and easy to deploy and to use as an effective support to independent living. Personalization can thus enhance the user's trust in the eHealth systems, and make them more readily accepted. Personalization can range from simply setting an alarm volume according to the user's hearing abilities and the ambient noise level, to the complex tailoring of the user's entire environment, including the eHealth services and devices.

The present document specifies a standard for personalization of eHealth systems. The personalization is achieved by maintaining and updating the user profile, consisting of a set of user related information, preferences and rules. The user profile depends on and is dynamically adapted to the user's context, preferences, physical and mental abilities, and other relevant parameters. The profile can then be used by eHealth systems to ensure an uniform user experience. The standard builds on the personalization and user profile concept described in EG 202 325 [i.1]. The generic personalization architectural framework is described in TS 102 747 [2] and the preferences for a wide range of services and devices (not particularly related to eHealth) are described in ES 202 746 [1].

The Design for All approach has been adopted in the present document. It means that accessibility is considered as something that can benefit people whether or not they have disabilities.

The URI root is upm-ns, identified by xmlns:upm-ns=http://uri.etsi.org/upm. The additional namespace which is health specific (xmlns:health-ns in the list below) has been specified in the present document. The other additional namespaces listed below are common with those listed in ES 202 746 [1].

Additional namespaces are:

- xmlns:profile-management-ns=http://uri.etsi.org/upm/profile-management;

- xmlns:personal-information-ns=http://uri.etsi.org/upm/personal-information;

- xmlns:connectivity-preferences-ns=http://uri.etsi.org/upm/connectivity-preferences;

- xmlns:interaction-preferences-ns=http://uri.etsi.org/upm/interaction- preferences;

- xmlns:notifications-ns=http://uri.etsi.org/upm/interaction-preferences/notifications;

- xmlns:communication-handling-ns=http://uri.etsi.org/upm/communication-handling;

- xmlns:consume-content-ns=http://uri.etsi.org/upm/consume-content;

- xmlns:way-finding-ns=http://uri.etsi.org/upm/way-finding;

- xmlns:health-ns=http://uri.etsi.org/upm/health.

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1 Scope

The present document provides a standard relevant to management of user profiles for personalisation of eHealth systems and services according to users' preferences and needs. Personalization of eHealth systems includes personalization of the eHealth information and interaction. It specifies standardized elements of profiles including information and preferences.

Profile aspects within the scope of the present document are:

- those provided for the primary benefit of the end-user;

- those where the end-user has rights to manage the profile contents;

- those where the end-user has the right to have a dialogue with the information owning stakeholder.

2 References

References are either specific (identified by date of publication and/or edition number or version number) or non-specific. For specific references, only the cited version applies. For non-specific references, the latest version of the reference document (including any amendments) applies.

Referenced documents which are not found to be publicly available in the expected location might be found at http://docbox.etsi.org/Reference.

NOTE: While any hyperlinks included in this clause were valid at the time of publication ETSI cannot guarantee their long term validity.

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2.1 Normative references

The following referenced documents are necessary for the application of the present document.

[1]   ETSI ES 202 746: "Human Factors (HF); Personalization and User Profile Management; User Profile Preferences and Information".

[2]   ETSI TS 102 747: "Human Factors (HF); Personalization and User Profile Management; Architectural Framework".

[3]   IETF RFC 4480: "RPID: Rich Presence Extensions to the Presence Information Data Format (PIDF)".

[4]   CLDR: "Unicode Common Locale Data Repository", "measurement-unit" supplemental data.

NOTE: See http://cldr.unicode.org/.

[5]   ISO 80000-1:2009: "Quantities and units - Part 1: General".

[6]   vCard: The Electronic Business Card, Version 2.1.

NOTE: See: http://www.imc.org/pdi/vcard-21.txt.

[7]   ETSI TS 102 334 (all parts): "Network Address Book on fixed network".

[8]   XML Schema Part 2: Datatypes Second Edition (October 2004).

NOTE: See http://www.w3.org/TR/xmlschema-2/.

2.2 Informative references

The following referenced documents are not necessary for the application of the present document but they assist the user with regard to a particular subject area.

[i.1]   ETSI EG 202 325: "Human Factors (HF); User Profile Management".

[i.2]   ETSI EG 202 421: "Human Factors (HF); Multicultural and language aspects of multimedia communications".

[i.3]   ETSI SR 002 564 (V2.0.0): "Applicability of existing ETSI and ETSI/3GPP deliverables to eHealth".

[i.4]   eHealth Ministerial Declaration: "The Contribution of ICT to Health. Ministerial Conference and Exhibition"; Brussels, 22-23 May 2003.

NOTE: Available at:
          http://ec.europa.eu/information_society/eeurope/ehealth/conference/2003/doc/min_dec_22_may_03.pdf.

[i.5]   WHO: "International Classification of Diseases (ICD)".

NOTE: Available at: www.who.int.

[i.6]   WHO: "International Classification of Functioning, Disability and Health (ICF)".

[i.7]   WHO: "International Classification of Health Interventions (ICHI)".

[i.8]   WHO: "Guidelines on the use of International Nonproprietary Names (INNs) for Pharmaceutical Substances".

[i.9]   Oh H, Rizo C, Enkin M, Jadad A: What Is eHealth (3): "A Systematic Review of Published Definitions", J Med Internet Res 2005;7(1):e1.

NOTE: See http://www.jmir.org/2005/1/e1/.

[i.10]   Eysenbach G. "What is e-health?" J Med Internet Res 2001 Jun 18;3(2):e20.

NOTE: See http://www.jmir.org/2001/2/e20/.

[i.11]   Mitchell J. "From telehealth to e-health: The unstoppable rise of e-health", Canberra, Australia: Commonwealth Department of Communications, Information Technology and the Arts (DOCITA); 1999.

[i.12]   "Integrating Community Equipment Services (ICES)" (January 2005): "Telecare".

[i.13]   Doughty, K., Cameron, K. and Garner, P. (1996): "Three generations of telecare of the elderly" Journal of Telemedicine and Telecare 2(2): 71-80.

[i.14]   ISO 215: "Documentation - Presentation of contributions to periodicals and other serials".

3 Definitions and abbreviations

3.1 Definitions

For the purposes of the present document, the following terms and definitions apply:

accessibility: ensuring that all sectors of the community have equal access to communications and online information

administrator: person who defines profiles with profile data

NOTE: Also known as profile administrator.

carer: individual who provides health or social care to the client

NOTE: Both professional and informal carers are included in this category.

client: individual receiving the eHealth service, to support independent living and/or using eHealth services for the care of his or her own health and wellbeing

eHealth service provider: provider of eHealth services to a group of people

formal carers: professional providing care for the client

health/care professionals: professionals (e.g. clinicians, doctors, occupational therapists, social workers) involved in the assessment of clients and delivery of more specialist care than that provided by carers

informal carers: relatives, neighbours, friends or volunteers providing care for the client

profile: set of user related information, preferences, rules and settings which affects the way in which a user experiences terminals, devices and services

NOTE: The use of the word profile in the present document implies user profile unless otherwise stated.

profile provider: entity (e.g. company such as a service provider, organisation such as a special interest or affinity organization) that provide profiles and associated services

rule: statement that can be interpreted by the profile system to produce or limit an action

state: aspect of users and their devices and services

template: set of rules and settings provided by an entity as a starting point for the user for the creation of their profiles

usability: extent to which a product can be used by specific users to achieve specific goals with effectiveness, efficiency and satisfaction in a specified context of use

user: person using ICT services

user profile: See profile.

3.2 Abbreviations

For the purposes of the present document, the following abbreviations apply:

ACR-NEMA	American College of Radiology - National Electrical Manufacturers Association
ADL	Activities of Daily Living
CEN	Comité Européen de Normalization
COPD	Chronic Obstructive Pulmonary Disease
DICOM	Digital Imaging and Communications in Medicine
EAACI	European Academy of Allergy and Clinical Immunology
EHR	Electronic Health Record
FIC	Family of International Classifications
HL7	Health Level 7
ICHI	International Classification of Health Interventions
ICT	Information and Communications Technology
IDR	Informatics for the Disabled and Rehabilitation
IFIP	International Federation for Information Processing
IHE	Integrating the Healthcare Enterprise
NLU	Natural Language Understanding
NPS	Nomenclature for allergy Position Statement
PCI	Primary Care Informatics
PHR	Personal Health Record
PPD	Personal Portable Devices
SDO	Standards Developing Organization
SFC	Scottish Funding Council
UPM	User Profile Management
WAO	World Allergy Organization

| WG | Working Group |
| WHO | World Health Organization |

4   Overview of the personalization and profile concept

4.1   Introduction

For the convenience of the reader, this clause provides an brief overview of the personalization and user profile concept as described in more detail in EG 202 325 [i.1]. Further information can also be found in ES 202 746 [1] which provides standardized user profile preferences and information. The personalization and user profile Architectural Framework is described in [2] (not restricted to eHealth personalization). The present document concentrates on the eHealth aspects of the user profile. From now on in the present document, the term "profile" will be used with the meaning "user profile".

4.2   What is a profile?

A profile contains details of the user and their personal requirements in a form that can be used by a system to deliver the required behaviours. When users wish to have the behaviour of devices or services personalized to their requirements, a profile will be required for:

- storing information, preferences and rules;

- making the information and preferences available to services/devices and when relevant also to other people.

Users require the data to be stored in a secure manner with user agreed levels of privacy applied to the availability and distribution of that data.

In the present document, the profile is often referred as if it is a single functional entity. However, parts of this profile may be distributed amongst a number of storage locations that include the user's services and devices. There may also be copies of profile data stored in devices or services and in a centralized location. Wherever the data is stored, the profile system will ensure that the data is synchronized when relevant. When new devices are acquired, factory set information and preferences may be updated by information and preferences copied from equivalent data that is already in the user's profile.

Major factors of the profile concept described in the present document, that distinguish them from profiles described in many other sources, are:

- the primary purpose of the profiles are to offer benefits to users;

- profiles contain information that allows users to configure services and devices to meet their individual needs;

- most of the data in the profile is considered to be owned by the user;

- the user can view all of the information in their profile in a form that is designed to be easy to understand;

- much of the information in the profile is intended to be applicable to a wide range of services and devices that are associated with the user;

- the user is usually able to modify most of the information in the profile (examples of exceptions when someone cannot modify information in the profile is when a child who might not be allowed to change most of the data, as their parents might have decided to configure the profile for them or clients who ask a carer to update the profile on their behalf).

4.3   Organization of the profile content

In general, a profile contains [1]:

- Information: data about or related to the user (e.g. name, address).

- Preferences: choices made by the user about a given parameter that will define or modify the system behaviour. More complex preferences can be expressed in the form of rules (see below).

NOTE: When something is considered essential to the user, it would be more appropriate if a preference is instead called a "need" (e.g. a blind user sets the modality to "sound"). However, for simplification, in the present document the word "preference" is used.

- Rules: statements that can be automatically interpreted in order to define or modify the system behaviour. These rules may:

    - express complex preferences;

    - activate or de-activate situation profiles.

More specifically, the profile is organized into several blocks. The major organisational units of the profile are:

- Personal information: data about or related to the user (e.g. name, address, location).

- Human centred preferences: These are the overall preferences that might apply across the user's usage of a wide variety of different devices and services.

  As these preferences are not mapped precisely to specific features of services and devices, they may be presented in ways that must be interpreted before they can be used as the definition for a precise setting for a service or device feature.

- Service/device category related information and preferences: The information and preferences in this clause are related to service categories (e.g. Communications services), further sub-categories of the service category (e.g. Realtime communication), and specific services/devices.

Information and preferences need to be associated with a scope, which includes:

- (groups of) services;

- (groups of) devices;

- (groups of) people (e.g. entries in an address book).

- A scope may be very narrow (e.g. one specific service) or very broad (e.g. preferred language for all my services).

The values of the profile information and preferences in the profile will be either:

- directly set by the user (or by someone else on behalf of the user);

- read from other profile information (e.g. from devices or services);

- set as the result of a rule that is contained in the user's profile.

Further details on the profile content for services and devices in general (not restricted to eHealth services) is described in ES 202 746 [1] on "User Profile Preferences and Information".

4.4   Profile extensions

4.4.1   Proprietary profile extensions

Because of the limited of standardization of the features of eHealth related services and devices, it is not possible to define a full set of standardized profile data related to these. However, the profile may still contain information and preferences related to these as proprietary profile extensions. As stated in ES 202 746 [1], in addition to profile data items as defined and listed in the present document, it is possible for eHealth service developers and device manufactures to include proprietary profile data items in the profile which shall be identifiable as proprietary (e.g. specify the company and/or product identifier for which the proprietary information and preferences are intended for). Proprietary profile extensions are outside the scope of the present document.

4.4.2   Additional standardized information and preferences

In addition to profile data items as defined and listed in the present document, it is expected that there will be a need for future additional standardized information and preferences, for which new versions of the present standard may be developed.

4.5   Templates

Profiles can contain a very large number of settings and preferences which would be difficult to set up unaided. When users first create profile specifications, the creation task can be greatly simplified if the profile specifications are created from templates. The template provides a set of rules and settings that act as a starting point for users when creating their profiles, and these can be further amended by the user to suit their individual needs. Templates can be provided to the user from a number of different sources. Typically, templates would be used to create a personal default profile specification. Some templates for creating typical situation profiles would then also be provided. The use of templates will typically be in combination with a wizard guiding the user while defining their profile.

There may be parameters for which defaults are not appropriate and where the profile system will force the user to set their own value e.g. where it might result in a potentially dangerous health condition or if it is legally required for the user to make an explicit decision for themselves. When prompting the user for a value, the profile agent may:

- request explicit user input;

- propose a range of options from which the user will have to chose one;

- propose a value to accept or reject and give the user a mechanism to specify an alternative value if they reject the proposed value.

Further information and guidelines on templates can be found in clause 9 of EG 202 325 [i.1].

4.6   Profiles and user views

4.6.1   Situations, context and the scope object

Users move between situations throughout the day (e.g. at home, driving, working), and also users may change depending on their specific health condition. In each of these situations, users may have different needs for how they would like their ICT resources arranged. Wherever a user wishes to have different behaviour from their ICT it will first be necessary to identify criteria that uniquely define the situation. These criteria are captured as rules that defines when a Scope object is active (i.e. when it is isActive method evaluates to TRUE). Hence the user concept of a "situation" is represented in the profile system by a Scope object.

Clause 5.4.4 in TS 102 747 on "Personalization and User Profile Management: Architectural Framework" [2] shows very flexible ways in which the profile data is modified according to the context. However, users will be unable to understand all of the possible implications of the dependency of individual data items on context. For this reason, it is necessary to introduce the concept of User Views of the profile. Although it is possible to create any number of specialized views of the profile, two views that have been defined in EG 202 325 [i.1], and which are described to users as profiles, are the "Normal Profile" and the "Situation Profile". The view that is described as the "Normal Profile" shows all of the profile data that will be applied when no specific user-defined situation applies. This view can be achieved by creating a view of the profile that shows the values of profile data when no Scope object other than the "Normal" Scope object have been activated.

Whereas the "Normal Profile" view shows the values of the items in the profile, it is useful to show the values of profile data that may need to be set to values relevant to a user-determined situation. There is therefore a need for another view which corresponds to the user concept "situation". Such a view is described in user terms in EG 202 325 [i.1] as the "Situation Profile". In this view the user can see the values assigned to profile data items that may need to have a special value set in that situation. The situation profile view will contain fewer profile data items than the "Normal Profile" view, as it will contain only those data items which are different in that specific situation (i.e. only profile data items associated with the Scope object that represents the user's "situation").

Profile providers may also offer other views of the profile to users. For example, users may wish to see all of their profile as it will be in a particular "situation", not just the standard view that shows those profile data items that are uniquely configured for the current situation.

Profile users should be allowed to view their profiles making use of these user views and, if they have administrator rights, should be allowed to modify the profile data that they see in these views. Modifications to profile data in a user view that shows a "Situation Profile" is a means to allow the modification of the Profile-Item-Attributes associated with that "situation" (i.e. associated with the Scope object that represents that "situation").

Situation profiles can be activated:

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- manually, e.g. the user choosing the relevant situation (Scope object) from a menu;

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- automatically, e.g. the system detects that a Scope object has been activated and activates the appropriate "situation profile";

- combination of automatically and manually, e.g. the system detects that a Scope object has been activated and asks the user if they want the corresponding situation profile to be activated, and the user accepts.

NOTE: Clause 4.7 describes how many specialised health states, that in many ways are similar to situation profiles, will not be user selectable in menus and will not be presented to users to accept or reject.

Conflicts may appear when two (or more) Scope objects are simultaneously activated, which would result in an attempt to set the same profile data to different values. To avoid this, the profile system needs to determine which of these alternative values shall be applied. Therefore, priorities are assigned to "Situation Profiles" and/or profile data items. In the profile system, the priorities are attributes of the Scope objects that are associated with "Situation Profiles" and individual profile data items. If there is an attempt to set two (or more) different values for an item of profile data, then the value of the profile data that is associated with the Scope object with highest priority is set. The mechanisms for handling conflicts and dealing with the situation when priorities still do not resolve a conflict are described in more detail in TS 102 747 [2]. Table 5.3.3 (Scope class) in [1]. gives the specification of the priority attribute of the Scope object, and defines ranges of priorities to be assigned to different categories of Scope objects (determined by the scope-category attribute of the Scope object).

Profile provider support should assist users in defining priorities to avoid potential conflicts.

4.6.2   Avoiding conflicts by using templates

Potential conflicts (when two or more Scope objects, are trying to set the same data to different values), may be resolved by the use of a well designed set of pre-defined templates that assign priorities to preferences in a way that eliminates conflicts for most probable combinations of situations (Scope objects).

It would be expected that if profile providers assist users to create their profiles by means of a "creation wizard", the wizard would make use of such a coherent set of templates and would thus create an initial profile setup where conflicts are eliminated or confined to extremely unlikely combinations of situations.